

University of Illinois Center for Population Health and Health Disparities
Richard B. Warnecke, PhD, Principal Investigator

Introduction and Overview of the entire CPPHD Application.

The CPPHD will use a model adapted from a paper by Berkman and Glass.¹ It describes a continuum of variable clusters or “upstream to downstream factors” that affect health. Thus, the CPPHD has four projects that focus on each of the general elements in the Berkman/Glass model. However, although we are using the model, we are applying it to neighborhood area clusters that have been defined and well characterized by Sampson, Earls and others^{2,3,4,5}. These authors have used these neighborhood clusters to focus on the effects of neighborhood environment and social organization on criminal behavior and juvenile delinquency. Others have shown independent effects of collective neighborhood properties on health⁶⁻¹¹. Moreover, there are 343 neighborhood clusters in the Sampson-Earls dataset, thus, we can also analyze the neighborhood variation at a level, which is often not possible in other research. There are sufficient independent variables that we can characterize the neighborhood clusters on several dimensions. Finally, because the neighborhoods are recognizable units, as part of our collaboration we can actually get feedback regarding hypotheses about neighborhood impact on the models we plan to test and actually involve the community partners in the research. At the next level are the individuals’ social networks and, as with the neighborhood, there are sufficient numbers of networks to allow us to study their aggregate influence on individual partners and how the context (neighborhood) affects their form and influence. The psychosocial elements will come from two sources: cancer patients identified through the Illinois State Tumor Registry and interviews with women seeking diagnosis. From these interviews we can obtain self-reports of cultural beliefs and behavior, and from the chart data we can define the pathways from detection to treatment. These analyses will be integrated in interdisciplinary papers developed through the Center.

Center Aims: This Center has four aims: 1) to use the elements of the Berkman and Glass model to address the disparity that we have defined as the center’s theme, “The Apparent Disconnect between Rates of Screening and the Stage of Diagnosis of Breast Cancer by Race and Ethnicity. The “disconnect” arises because African American women and Hispanic women increasingly report receiving mammography at rates equivalent to those reported by Caucasian women. Yet African American and Hispanic women continue to experience higher breast cancer mortality rates compared to Caucasian women; 2) to develop this model and the variables to the point where it can be tested with breast cancer and then eventually, be extended to other cancers where similar disparities exist; 3) to develop the capacity to conduct multidisciplinary research that addresses the biological, behavioral, social and environmental factors that affect prognosis and outcome of cancer; 4) to demonstrate through a sustainable partnership with one or more community-based organizations the use of theory-driven interventions which, if shown to be successful, can be integrated into the way in which cancer is detected and managed in the community. Thus, we view the present set of projects as a first step in establishing an approach to questions of population health and health disparities that will characterize the ongoing work of the CPPHD and sustain its activity over time. We are fortunate to have strong support from both the Director of the Cancer Center and the Vice Chancellor for Research at UIC to pursue these goals.

Overview of Program Elements:

There are four projects and four cores proposed for this Center.

Project 1: Neighborhood and Individual Effect on Stage at Diagnosis (Richard B. Warnecke, PI). This project explores the relative capacity of individual and ecological factors to account for the apparent disconnect between the converging rates of mammography across these ethnic groups and the continuing disparity in stage at diagnosis. This project has four specific aims: Aim 1: To measure the relative effects of community level variables on the prevalence of late stage diagnosis in different Chicago neighborhoods. In this analysis, the effect of community-level variables on the degree of late stage breast cancer diagnosis in neighborhoods throughout the city of Chicago will be measured. Aim 2: To measure the interaction between community variables, individual-level, psychosocial and cultural variables, and access to care on both mammography history and stage of diagnosis. We will seek to account for the disparity between mammography rates and stage at diagnosis by examining the percentage of 1,200 patients accrued through the Illinois State Cancer Registry (ISCR) that are diagnosed at later stages of breast cancer, defined as a pathologic stage of II, III or IV. Aim 3: To perform a sub-analysis of the factors affecting the elderly (age 65-79 year old) who are diagnosed with breast cancer. In this analysis, several additional neighborhood-level demographic factors will be added to the previous ecological and individual level analyses (Aims 1 and 2) to see whether the elderly are

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affected by additional factors beyond those found in the analyses performed in Aims 1 and 2. It is hypothesized that in some kinds of neighborhoods, the elderly suffer from greater isolation from knowledge about breast cancer and make less use of medical resources, resulting in a greater proportion of diagnoses with late stage breast cancer. Aim 4: We will collaborate with our community partners to design a community intervention strategy that will build on the results of the research undertaken to complete aims 1-3. This intervention will address the community resources available to improve access to screening mammography and general preventive health care, and will evaluate ways to address those resources that are not available. We will work with our community partners to examine the indicators that predict later stage diagnosis, particularly in Aim 1. Our partner in the community will be an existing coalition of clergy, health professionals, community residents and businesspersons that has been brought together by a community-based organization, The Healthcare Consortium of Illinois. We will work with our community partners and one of their consortia; a coalition of 200 churches, to examine how combined environmental, organizational and educational interventions can increase early stage diagnosis.

Project 2: Social Network Effects on Breast Cancer Prognosis (Yoosik Youm, PI). This study will examine how racial/ethnic disparities in breast cancer stage at diagnosis are related to the patients' embeddedness in social networks. The patterns of social support and information flow through networks, and their contributions to ethnic disparities in stage at diagnosis, have not been studied before. These patterns of support may vary by age, race/ethnicity or some combination of these as part of the social framework in which these individuals are embedded. This project will identify networks of the 1,200 cancer patients interviewed for Projects 1 and 4 and the 450 women waiting for diagnosis interviewed in Project 2. Aim 1 will generate a series of network characteristic indices that will characterize the effects of social interaction on women's breast cancer related behavior, controlling for race and ethnicity. Aim 2 will use network interviews to predict a patient's health related attitudes, beliefs, knowledge and behavior based on those of her network. Aim 3 will examine the effects of networks on stage at diagnosis, and the interaction of networks with neighborhood variables defined in Project 1. Aim 4 will examine the effects of age on social networks and how the effect of age varies by race/ethnicity, in order to determine if older women use networks differently in deciding whether to obtain screening mammograms and seek diagnoses.

Project 3: Breast Cancer Delay in Black, Hispanic and White Women. (Carol Eastwing Ferrans, PI) The purpose of this study is to identify factors that contribute to delay in seeking medical care for breast cancer for African American, Hispanic and White women in Chicago. This study seeks to identify variables contributing to later stage of breast cancer at medical presentation, focusing primarily on women in middle and lower income groups. The information provided by this study will be used to tailor interventions to decrease delay in these groups, which will be pilot tested in the final years of this study.

Aim 1. To identify the cultural beliefs about breast cancer contributing to delay in Black, Hispanic, and Caucasian women in Chicago, and to examine the influence of cultural orientation on delay. Aim 2. To develop versions of an instrument to assess cultural beliefs contributing delay for Black, Hispanic, and Caucasian women, and to validate the measure of cultural orientation and other instruments to be used in this study. Aim 3. To examine the relationship between the perceived consequences of delay and the time to first contact with health care providers and identify the individual, social, and economic factors contributing to delay in African American, Hispanic, and white women in Chicago. Women from the three ethnic groups, who are similar in terms of age and socioeconomic status, will be compared to identify similarities and differences among the groups in the factors that contribute to delay. Aim 4. Develop and pilot test interventions to decrease delay in the three ethnic groups, in collaboration with community partners.

Project 4: Mediators of Ethnic Disparity in Breast Cancer Prognosis (Garth Rauscher, PI). This project focuses on the most proximal issues related to the theme of the Center. The study will use data from interviews with 1,200 newly diagnosed breast cancer patients and data from their hospital charts. Three "mediating" variables are hypothesized to intervene on survival by influencing the timing of detection, diagnosis and treatment. These variables are the way in which the breast cancer was discovered (Path to Detection), the interval from breast cancer discovery to contact with the health care system, (Time to Contact), and the interval from first contact to treatment initiation (Time in System). A fourth variable (Treatment Given) is hypothesized to influence prognosis independent of disease stage. Project 4 has six specific aims. Aim 1 will explore ethnic variation in prognostic markers. Aim 2 will examine ethnic variation in mediating variables. Aim 3 will examine the relationship between mediating variables and prognostic markers. Aim 4 will

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incorporate neighborhood variables from Project 1 to examine the role of individual- and neighborhood-level socioeconomic status on ethnic disparities in mediating variables. Aim 5 will examine the role of individual- and aggregate-level health care system factors on ethnic disparities in intervening variables. Finally, Aim 6 will incorporate variables defined and validated in Project 3 to examine factors associated with treatment variation.

There are four cores proposed for this center.

Core A: The Administrative Core will be responsible for the management of the Center and maintaining the collaborations on which it is based.

Core B: The Case Ascertainment Core will be responsible for rapid ascertainment of eligible cases and medical record abstraction at the 60 hospitals in Chicago. Core B will administer a sampling plan developed by Core C, the Survey Core, to ensure that we accrue sufficient numbers of African American and Caucasian patients and that all cases not sampled are reviewed to determine if any might be Hispanic. Also, all cases for which no race or ethnicity is recorded in the record will be examined by the staff of this core to ensure that no Hispanic cases are missed.

Core C: The Survey Methods Core will conduct face-to-face, home interviews with 1,200 patients identified by the Ascertainment Core. They will devise a sampling plan to select African American and Caucasian patients with known probabilities. The Survey Core will obtain written consent from the patients for review of their records. As part of the patient interview interviewers from Core C will also identify the network members of the 1,200 cases. Core C will use network information obtained from the women interviewed in Project 3 as well as from the breast cancer patients to create a network sample for interviewing. Telephone interviewers at the Survey Research Laboratory will interview all network members.

Core D: The Statistical Core will oversee the creation of study data files and ensure that they are updated with any new measures created by members of project teams. The Statistical Core will also oversee and consult with the project teams on all analyses as required. They will participate in writing teams from each project.

Interdisciplinary Strategy:

The CPHHD is built around a multidisciplinary research strategy that already characterizes the programs in Cancer Control and Population Science (CCPS) at the University of Illinois at Chicago Cancer Center. The CCPS already contains a strong interdisciplinary tobacco program and is developing a program in Patient Survivor Studies that will also be interdisciplinary. Also it is currently training predoctoral and postdoctoral fellows in multidisciplinary research in Cancer Control and Population Science. Dr. Warnecke is the Principal Investigator of an R25, Career Development and Cancer Education Grant that includes programs in the College of Liberal Arts (Sociology and Psychology), College of Nursing, College of Pharmacy, College of Urban Planning and Public Affairs and the School of Public Health. This Center will be the primary training site for the R25 fellows.

The Center will be physically located in the Health Research and Policy Centers (HRPCs). The School of Public Health administers the HRPCs but it is an all campus unit composed of centers that focus on multidisciplinary strategies for addressing health research and policy. The Cancer Center is also an all-University unit administered through the College of Medicine. The location of the Cancer Control, Population Research and Education unit of the cancer center in the HRPCs ensures that there is regular access to the multidisciplinary social and behavioral science research environment that exists there. Finally, there is history. Dr. Warnecke has vast experience in working with multidisciplinary teams and had funded P01 support from 1985-1997 that was always a multidisciplinary team of investigators. The Cancer Center has provided budget for an on-going program addressing research with persons of color. The core members of this research team were part of that activity, which focused on multicultural and multidisciplinary issues in collaboration.

It is not possible to conduct the type of research proposed here in an environment that lacks interdisciplinary collaboration. The investigators comprise a multidisciplinary team. Dr. Warnecke, the Principal Investigator for Project 1 is a sociologist/epidemiologist. Dr. Barrett is a demographer/sociologist. Dr. Giachello has a degree in social work and is a graduate of the Center for Health Services Research at the University of Chicago. Ms. Willis is a masters-prepared nurse as is Ms. Davis and Dr. Ramos is a physician. The Principal Investigator on Project 2, Dr. Yoosik Youm is a sociologist trained in network analysis, Dr. Johnson is a medical sociologist. On Project 3, Dr. Ferrans has a Ph.D., in nursing with training in psychometrics and research theory. Dr. Bonner is a Ph.D. nurse. Dr. Johnson is a Medical Sociologist. Dr. Garth Rauscher, Ph.D. in epidemiology, leads Project 4. His co-investigators are Clara Manfredi, Ph.D.

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sociology, and Faye Davis, Ph.D. epidemiology. The leaders of Center are Dr. Warnecke, Director; Dr. Ferrans, Deputy Director; Dr. Bowman, Ph.D. (Psychology) Co-Director; and Ms. Virginia Martinez, JD., Co-Director. Dr. Davis is the Core Leader of the Ascertainment Core and Dr. Johnson is the leader of the Survey Core; Ms. Parsons (MA Sociology) is the co-leader of the Survey Core. Dr. Michael Berbaum (Ph.D. Psychology) is the leader of the Statistical Core and the co-leaders are Richard Campbell (Ph.D. Sociology) and Donald Hedeker (Ph.D. Psychology).

Core A describes the proposed administrative structure of the Center. Central to the administration is the Center Steering Committee (CSC). It will meet monthly and will set the intellectual and administrative policy for the Center. Key aspects of the Steering Committee's role include planning interdisciplinary papers and new research. Overall, the work on this project requires an interdisciplinary team and that have been assembled.

Setting and Facilities:

The CPHHD (as noted in the attached letter from Dr. Hoffman, Director of the Cancer Center) will be a central component of the Cancer Center's program in Cancer Control and Population Sciences (CCPS). Dr. Hoffman has agreed to locate the program in the Health Research and Policy Centers because it will thrive in the interdisciplinary environment there. Nevertheless he continues to support the program and has made tangible, financial support available to this Center should it be funded. He has committed to continue support of the program with the International Center for Health Leadership Development (ICHLD) and these funds are being used to support most of Ms. Willis' time on Project 1. This is a direct extension of the work that she has been doing to help establish this Community Collaboration Component described in Dr. Warnecke's project and in Dr. Ferran's project. There is also a letter from the Vice Chancellor for Research at the University. He has agreed to match the contribution of the Cancer Center with \$200,000 in pilot research funds over the five-year period to expand the Center's program. Finally, the Cancer Center currently supports Dr. Warnecke for a part of his salary that is not covered by grant funding. This support will continue making it possible for Dr. Warnecke to be available to the Center beyond the time covered by the budget in the proposal.

Overall, the Center fits closely with the general orientation and commitment of the University to the City of Chicago and its diverse population. The College of Urban Policy and Public Affairs in which the Survey Research Laboratory and the Institute for Research on Race and Public Policy are located is completely focused on the University's urban mission. The School of Public Health and other units of the University also have very strong commitments to the communities that are also the focus of this Center. Thus, overall there is tangible commitment in the support from the cancer center and the University. Finally, the interaction between the R25 and the Cancer Center will ensure that there is a lively, interdisciplinary environment that includes young scholars as well as experienced investigators.

CPHHD Organization and Administration:

The organization and administration of the CPHHD is detailed in Core A. Dr. Warnecke will be the Center Director. He has more than thirty years experience in interdisciplinary research on cancer issues, particularly addressed to populations that experience disparities in access to and benefits from health care associated with race, ethnicity and socioeconomic status. He has extensive experience in evaluating community outreach programs and good working relationships with the potential partners for this Center. Dr. Warnecke developed his experience in directing interdisciplinary research as Director for 15 years of the Survey Research Laboratory of the University of Illinois. He had an active P01 addressing smoking cessation among populations at high risk for smoking and particularly women with high school or less education. The P01 was interdisciplinary and produced papers that reflected an interdisciplinary perspective. He was also a consultant for three years to the Office of Special Populations Research at the National Cancer Institute. Dr. Carol Ferrans will be the Deputy Director. She is well known for her work in quality of life issues in health care. The Ferrans and Powers Quality of Life Index was first published in 1985, is available in 12 languages, and has been used in more than 18 countries. Dr. Ferrans research has focused on cross-cultural issues in the assessment of quality of life, including approaches to increase validity of data and participation in research for minority populations in the U.S. A significant part of her work has focused on the development of culturally specific measures for African Americans and Mexican Americans, and has been funded by the National Cancer Institute (NCI) and the National Institute of Nursing Research (NINR). Dr. Ferrans' most recent study (NCI) examines cancer survivorship issues for African Americans, focusing on the impact on quality of life and barriers to cancer screening. In addition, she is the mentor for two studies exploring the effect of trust/mistrust

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in health care providers, focusing specifically on the effect on cancer screening and health care decision making for African Americans. She and Dr. Warnecke are collaborating on several other projects.

All decisions regarding the use of Center Resources, new research or center participants, and other policy will be made by the Center Steering Committee (CSC) which will meet monthly. At least one community representative, Margaret Davis, RN, the person with whom we will work on the community-based research project, will be a member of that Committee. There are diagrams of the organization of the Center and its relationship to the Cancer Center in Core A.

Detailed Description of the Interdisciplinary Collaboration

All the proposed projects are interdisciplinary as reflected in Table 1. The focus of the Center will always require interdisciplinary research teams. Dr. Warnecke's experience has been in working with interdisciplinary teams of researchers. His P01 support from 1985-1999 was interdisciplinary as have been most of the funded research projects on which he has worked. Dr. Ferrans who will be the Deputy Director of the Center is also committed to multidisciplinary research as exemplified by her work to date. The key professional staff (Principal Investigators and Co-investigators) are from Nursing (Dr. Ferrans and Dr. Bonner), Public Health—Epidemiology (Dr. Davis, Dr. Warnecke, and Dr. Rauscher), Public Health--Community Health Sciences (Dr. Manfredi), Public Health—International Center for Health Leadership Development (Ms. Martinez and Ms. Willis), Ms. Willis is also a Public Health Nurse, School of Public Health--Biostatistics (Dr. Berbaum and Dr. Hedeker), Liberal Arts and Sciences--Sociology (Dr. Barrett, Dr. Campbell, Dr. Youm, and Dr. Warnecke), Urban Planning and Public Affairs--Public Administration (Dr. Warnecke and Dr. Johnson, Ms. Parsons), College of Urban Planning and Public Affairs—Institute for Research on Race and Public Policy (Dr. Bowman), Medicine, (Dr. Wolter, Rush Medical Center and Dr. Marcus, Cook County Hospital), School of Social Work (Drs. Giachello and Ramos), and Nursing—Healthcare Consortium of Illinois (Ms. Davis). Table 1 provides a graphic presentation of the distribution of disciplines by project.

Several strategies are “built into” the design and administration of the CPHHD that will ensure that the focus is interdisciplinary. First is the process of variable construction. Although the projects will be conducted concurrently, they are organized and presented in order of their proximity to the issue of the “disconnect” and disparity in outcomes related to breast cancer survival. Each project contributes variables that will be used by the other projects in their analyses. There are eight sources of data that are used in the four projects.

- The Community Survey from the Harvard Project on Human Development in Chicago Neighborhoods from which the community organization variables will be drawn, (Primary study: Project 1)
- 1990 and 2000 Census data from which we will construct the structural characteristics of the communities, (Primary Study: Project 1).
- Data from the Metropolitan Regional Transit Authority that will enable us to map the public transportation routes and time required for women to reach their sources of health care and mammography, (Primary Study: Project 1).
- 1,200 interviews with patients ascertained in cooperation with ISCR under rapid case ascertainment procedures, (Primary Studies: Projects 1,2,4).
- 450 interviews with women, who are not known to have breast cancer but who are waiting diagnosis, (women waiting diagnosis who are ultimately diagnosed with breast cancer will become part of the sample of 1,200 patients). (Primary Studies: Projects 2 and 3.) Projects 1 and 4 will use data from interviews with women with a cancer diagnosis.
- Interviews with 4,066 members of networks identified in the interviews with 1,200 patients and 450 women waiting for diagnosis.
- Chart data from both the 1,200 hundred patients and the 450 waiting for diagnosis, (Projects 1,3,4)
- Aggregate data on stage of diagnosis (1996-2000) obtained from ISCR. (Project 1).

Each project has its own analysis plan and will require different combinations of the data for that purpose. However, as the aims of each project indicate, outcomes from each project will provide variables for the others. So, for example, Youm (Project 2), Ferrans (Project 3), and Rausher (Project 4) will use the “social organization” variables and census measures developed by Warnecke and Barrett in Project 1 in their models. Similarly, Ferrans will use the properties of networks developed by Youm and Johnson in their aggregate level models. Warnecke, Barrett Youm and Johnson will conduct a joint analysis of neighborhood and network level

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effects on stage of diagnosis. All studies will use the individual level variables developed by Ferrans and Johnson in Project 3. Finally, Rauscher and his team will use medical record data to develop indicators of the timing of presentation and treatment for breast cancer, and measures of prognosis, measures that will be used as outcomes for other projects.

Another very important aspect of interdisciplinary collaboration will be the monthly meeting of the CSC. This venue will be the place where results of individual project analyses will be presented and discussed by the entire CPHHD team. These presentations will ensure that the investigating team is informed all aspects of the CPHHD's work and therefore have clear opportunities to develop collaborative analyses and new projects. This process will begin as the work proposed by Ferrans and Johnson in Aims 1 and 2 of their project is completed. That activity will produce the individual level measures to be used by other studies and ensure that they are appropriate and valid for the populations that are the focus of the research program of CPHHD. A second interdisciplinary collaboration will arise as the interview schedules for the survey are developed. Limitations in resources will require decisions about which of the measures that are proposed to be collected at the individual level will be on which survey. The interviews with the network members will be 30 minutes. Those with the patients and those with women waiting for diagnosis will last 60 minutes. The differences in length will require that CSC members working with network data develop preliminary analytic plans that consider what comparisons between the two samples require common data.

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Table 1: Interdisciplinary Make-up or Projects and Cores

Discipline	Projects and Cores							
	Warnecke Project 1	Youm Project 2	Ferrans Project 3	Rauscher Project 4	Core A	Core B	Core C	Core D
Nursing	2		2		1			
Medicine	1		1	1		1		
Epidemiology	1			2				
Sociology	2	2	1		1		2	1
Demography	1							
Psychology			1		1			2
Biostatistics	1	1	1	1				3
Law					1			
Social work	1							
Tumor Registrar						2		

Measurement development is also expected to produce interesting methodological results that will add to our understanding of how the concepts at each level of the Center model can be assessed cross-culturally and in different social contexts. We will also be able to add to the literature on how individual and ecological variables behave in analyses that use multi-level data. These methodological studies will also have to be planned before the developmental work starts in order to be sure that the design is appropriate to answer the questions.

In previous interdisciplinary research projects an important element in fostering interdisciplinary collaboration has been the creation of writing and analysis teams that assume responsibility for data analysis relevant to more than one component of the research agenda. The CSC will be the forum where plans for cross-project analysis will be made and discussed. Preliminary drafts of papers for publication and for presentation will be read and discussed at the CSC meetings. This is a point at which the general aim of creating a center-wide culture will be reinforced.

New research supported by pilot funds and new proposals will also come from the Center as the work progresses. Our primary strategy is to base new research, especially interventions, on the outcomes of the current research projects. Also high on the list of research priorities will be interventions that can be evaluated and integrated into health care delivery in the communities that participate in the research. Since each project is working on a different component of the issues related to addressing disparities, the interventions based on the outcomes will of necessity be cross-project and interdisciplinary.

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Another advantage of the CPHHD is that it will probably attract new researchers and provide opportunities to expand the research agenda of the CPHHD and of the Cancer Center more broadly. The CPHHD's physical location in the HRPCs will also facilitate increased interdisciplinary activity of both Centers. Similar synergy is expected from our collaborations with Dr. Giachello and the Midwest Latino Health Research and Policy Center, Dr. Bowman's Institute for Research on Race and Public Policy and the International Center for Health Leadership Development. These potential collaborations across existing centers at the University will add to the general urban orientation and commitment to the multi-cultural populations at the University of Illinois at Chicago.

These potential interactions present opportunities and challenges that must be collectively addressed by the current participants. Adding investigators or projects may affect Center resources or the on-going, primary research agenda. CSC will be the place where these decisions are made as a key aspect of the overall planning process and how the Center resources will be invested in new research.

We will also encourage investigators to collaborate in pilot research suggested by individual study outcomes. We will give priority to projects that include interdisciplinary teams composed of investigators involved with the CPHHD and those not involved. Given the R25 and the support in there for research, particularly for the postdoctoral fellows, we will also encourage pilot work that combines interdisciplinary work and young investigators who are in the R25. By combining funding on creative projects that require interdisciplinary collaboration we will be able to move new ideas along more quickly and help younger investigators obtain their first funding.

Finally, we assume that the annual meetings of the Centers will be a venue when investigators from different Centers will interact. One outcome of that interaction could and should be interdisciplinary collaboration across centers. Such interaction will bring together investigators with varying interests that may not be available at a single institution.

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